Research in vulnerable communities, a long journey from vulnerability to empowerment

Farah Asif

Madam, 'Medical research is only justifiable if there is reasonable likelihood that the populations in which the research is carried out stand to benefit from the results of the research'

Barira Wahid has updated about epidemic of HIV in a named small geographical territory in Pakistan and its possible causes, in Lancet recent issue.[1] Writer has rightly identified discrimination and stigma associated with HIV/AIDS, in the context of socially conservative setting of Pakistan. Facts described in this write up reportedly came from PCR-based screening carried out by The Health Department at District Headquarter Hospital, Sargodha and study involving interviews of villagers who visited the laboratory. No information is provided if ethical approval from competent authority was obtained for this research activity. Similar questions arise like: Was the community or representative of the community aware of this research? Were the participants informed about the expected results and dissemination plan of this study? Were their appropriate protective measures in place before this vulnerable population can be studied? Did the participants have a chance to review this write up and approve this before publication? The ones who participated in this research, would they ever get to know what has been reported about them? Is there any thought about what would be the implications of this research report on the community which is being studied?

Article reports, "A substantial proportion of patients might have acquired the infection sexually, but they were reluctant in discussing their sexual relationships". With no mention of scientific basis and certainty, it is not clear what has led the authors to make this presumption of a sensitive nature in the context of the society and prevalent religious beliefs in the region. Legitimacy of this assumptive statement is questionable.

Progressively role of vulnerable populations has assumingly changed from passive to active, and it is clearly needed. San Code of Research Ethics 2017[2] is a unique expression of active role of vulnerable population. It is the first code of conduct for research to be developed by a vulnerable indigenous group called San, in Africa. The development of code is rooted in the history witnessing how San felt abused by researchers. In 2010, publication of genomic research involving San,[3] was unacceptable to San leadership. It bypassed their councils which existed and were charged with the role to protect their people from exploitative research. Trust project, has supported the development of san code, and Global code of conduct for research in resource poor settings.[4] Though it cannot replace existing guidelines and regulations, it sets out requirements which will be acceptable to San and other resource poor countries, if researchers would want to study their population.

Do we need more regulations and codes, and if yes, how many of these will be sufficient? The effectiveness and compliance of all regulations depends on core values like honesty, integrity and acceptance of legitimacy of proposed mechanism, which is unfortunately hard to monitor or implement. At the end, all what is needed is a commitment from researchers, that research in vulnerable populations should be conducted only if it falls in pre-defined Research priorities of vulnerable population, ensuring local representation in all stages of research including development, review and publication. Further any research activity involving vulnerable population should allocate a fair bit of resources to empower the vulnerable population under study.

Shaukat Khanum Memorial Cancer Hospital and Research Center, Lahore, Pakistan.

Correspondence: Farah Asif. e-mail: crc3@skm.org.pk

Disclaimer: None.

Conflict of Interest: None.

Funding Sources: None.

References

1. Braira W. An update on the severe outbreak of HIV in Kot Imrana, Pakistan. Lancet Infect Dis. 2019; 19: 241.
2. South African San Institute. San Code of research ethics. [Online] [Cited 2019 July 23]. Available from: URL: http://passthrough.fw-notify.net/download/249657/http://www.globalcodeofconduct.org/wp-content/uploads/2018/04/San-Code-of-RESEARCH-Ethics-Booklet_English.pdf
3. Schuster SC, Webb M, Aakrosh R, Lynn PT, Belinda G, Lindsay RK, et al. Complete Khoisan and Bantu genomes from southern Africa. Nature. 2010; 463:943-7.
4. Global Code of Conduct for research in resource poor setting. [Online] 2018 [Cited 2019 March 7]. Available from: URL: http://ec.europa.eu/research/participants/data/ref/h2020/other/hi/coc_research-resource-poor-settings_en.pdf.

https://doi.org/10.47391/JPMA.1449